

# **Evaluation of the provision of information on antenatal and newborn screening to women with learning disabilities in London**

# **Evaluation of the provision of information on antenatal and newborn screening to women with learning disabilities in London**

**Including evaluation of the PHE easy guides ‘Screening tests for you and your baby’**

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## Contents

Contents .....	3
1 Executive summary .....	4
2 Introduction.....	6
3 Evaluation aims and objectives .....	8
4 Methodology.....	8
5 Background on the easy guides .....	9
6 Qualitative feedback.....	10
7 Online Survey.....	25
8 Other tools to evaluate the easy guides .....	28
9 Conclusions, recommendations and further work.....	31
10 Limitations.....	34
11 Appendix.....	35

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## 1 Executive summary

This evaluation used mixed qualitative methods to try and understand the wider context of provision of information on antenatal and newborn (ANNB) screening to women with learning disabilities in London and evaluate the use of the PHE 'Screening tests for you and your baby' easy guides. More than 100 professionals and people with learning disabilities, in London and nationally, have provided input to the project.

The evaluation found that the easy guides are a useful tool, but that health and other services could improve certain areas to ensure effective communication and provision of information to women with learning disabilities in pregnancy. An additional consideration is women with a formal diagnosis of learning disability are the 'tip of an iceberg' of women who may need additional support with information provision, for a variety of reasons.

The positive feedback for the easy guides as they currently stand suggests **review and revision of the content and format of easy guides can take place when natural opportunities arise**. The primary revisions which could be considered are:

- The choice of **photos used and their specificity to content of text**
- A further **breakdown in the amount of text per photo**
- Further **simplification of text** and especially revision where possible of the use of **technical terms / jargon**

Awareness and use of this resource appeared variable across London, and among national online respondents. Therefore, **further work locally and nationally should be undertaken to raise the profile of this resource**.

**Very consistent feedback has been received from professionals and people with learning disabilities regards production of video content** to support the easy guides. **An easy guide video giving an overview of ANNB screening pathway** may be the **first material to consider producing**.

The evaluation suggested health professionals would value more information and training resources. As a first step it is recommend PHE consider **producing a 'top tips'** type document to support professionals **similar to 'Supporting women with learning disabilities to access cervical screening'**<sup>1</sup>

**Links made during this evaluation** with voluntary sector organisations and parents with learning disability **should be maintained to facilitate continued engagement of parents with learning disability in the review of easy guide materials and development of new materials**.

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<sup>1</sup> <https://www.gov.uk/government/publications/cervical-screening-supporting-women-with-learning-disabilities/supporting-women-with-learning-disabilities-to-access-cervical-screening>

This evaluation highlighted issues, and possible improvements, for supporting women with learning disabilities within ANNB screening and wider maternity services and systems issues locally and nationally. Areas for consideration include maternity unit pathways for learning disabilities, having a lead or person who acts as a point of contact or reference for learning disabilities, local and national training and competencies and resource sharing at local and national level. There is a ***need to take these issues forward within wider learning disability and maternity service / systems discussions in appropriate forums in London and nationally.*** Recommendations for initial actions following on from this evaluation are suggested.

## 2 Introduction

Screening is the process of identifying healthy people who may have an increased chance of a disease or condition. Those who are found to have an increased risk are then offered information, further tests and treatment as needed to reduce associated problems or complications.

Screening tests are offered during pregnancy to try to find any health problems that could affect the women or the baby. These are the antenatal and newborn (ANNB) screening programmes. The screening tests can help women make choices about care or treatment during pregnancy or after the baby is born. The screening tests offered during pregnancy in England are either ultrasound scans or blood tests, or a combination of both. In addition, some screening tests are offered for babies after they are born. Many of these screening tests need to be offered early in pregnancy or soon after birth. The current screening tests in England are as follows

In pregnancy:

- screening for infectious diseases (hepatitis B, HIV and syphilis)
- screening for inherited conditions (sickle cell, thalassaemia and other haemoglobin disorders)
- screening for Down's, Edwards' and Patau's syndrome
- screening for fetal structural abnormalities (18 to 21 week scan)

For newborns:

- newborn physical examination (screening of eyes, heart, hips, and testes)
- newborn hearing screening
- newborn blood spot screening (screens for sickle cell disease, cystic fibrosis, congenital hypothyroidism and six inherited metabolic diseases)

People with learning disabilities are a specific group known to have inequitable access to screening programmes in England<sup>2</sup>. Some women with learning disabilities may avoid maternity care because of lack of confidence, negative staff attitudes, lack of clear explanations of what is going on, inaccessible leaflets and fear of the involvement of social services<sup>3</sup>. A key finding of a systematic review of evidence on antenatal care for women with learning disabilities was that women struggle to

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<sup>2</sup> <https://phescreening.blog.gov.uk/2017/09/12/screening-inequalities-and-what-were-doing-about-them/>

<sup>3</sup> <http://www.pickereurope.org/news/capturing-experiences-seldom-heard-groups-providing-quality-maternity-experiences-parents-learning-disabilities/>

understand antenatal information communicated during pregnancy, which is often text based<sup>4</sup>.

Easy guide versions of the 'Screening tests for you and your baby' leaflet, which explains antenatal and newborn screening for women with learning disabilities, were launched by Public Health England (PHE) in February 2017<sup>5</sup>.

NHS England (London) has responsibility for commissioning antenatal and newborn screening across London. A key objective of NHS England (London) is to tackle inequalities in screening and hence it is very interested in how information on screening tests in pregnancy is given to women with learning disabilities. Little is known by NHS England (London) however, about women with learning disabilities and their experience with antenatal and newborn screening. NHS England (London) does not have data on the number of women with learning disabilities seen by units, how they are identified, how information is given and how personalised informed choices for screening are supported.

With the first anniversary of the launch of the easy guides, NHS England (London) felt this was an opportunity to understand both how this resource was being used and to understand the wider context of provision of information on antenatal and newborn screening to women with learning disabilities. An initial conversation with the national PHE team which produced the easy guides revealed it had not undertaken a formal evaluation of these resources and would welcome collaborating on a project to understand more about their use. The basis of an evaluation project was therefore formed; to engage a wide range of stakeholders and service users to understand better information provision for women with learning disabilities in London and at same time evaluate the easy guides.

Initial engagement was undertaken with a small group of experts from the academic, screening, learning disability and voluntary sectors. This produced four focal areas for the evaluation:

- How women with learning disabilities are identified in the context of maternity and ANNB screening services and the pathways then put in place
- How information provision is supported for these women, exploring materials used, staff training and capacity
- The PHE easy guides and how professionals use them
- The opinions of people with learning disabilities on the easy guides and other materials/support

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<sup>4</sup> Homeyard, Claire & Montgomery, Elsa & Chinn, Deborah & Patelarou, Evridiki. (2015). Current Evidence on Antenatal Care Provision for Women with Intellectual Disabilities: A Systematic Review. *Midwifery*. 32. . 10.1016/j.midw.2015.10.002.

<sup>5</sup> <https://phescreening.blog.gov.uk/2017/02/10/launch-of-easy-read-versions-of-screening-tests-for-you-and-your-baby/>

### **3 Evaluation aims and objectives**

This evaluation aimed to inform developments in the provision of information on antenatal and newborn screening (ANNB) to women with learning disabilities and to understand the role of PHE's easy guides in this context.

The objectives of evaluation were:

- To understand the wider context of provision of information on antenatal and newborn (ANNB) screening to women with learning disabilities in London
- To evaluate the use of the PHE 'Screening tests for you and your baby' easy guides in London
- To identify good practice around the provision of information on ANNB screening that can be shared
- To identify any gaps and further work that may be beneficial to be undertaken by a range of stakeholders including PHE, NHS England (London), providers and others
- To triangulate London findings with national opinions, through the use of an online survey and online professional engagement tools and through dissemination and discussion after the London evaluation is complete.
- To inform ongoing work around strategies and standards to address inequalities, such as the PHE screening inequalities strategy

### **4 Methodology**

This evaluation used mixed qualitative methods. Semi-structured interviews were conducted with key informants across London. Participants were selected using purposeful sampling and included ANNB screening providers, maternity and learning disability professionals and voluntary sector support and advocacy groups. A snowball technique was used to identify further key informants from initial interviewees. In addition, an online survey (outlined below) generated further key informants. The topic guide for the interviews is in appendix 1. In addition to full semi-structured interviews a number of shorter telephone exchanges and email correspondence were received.

Based on the semi-structured interview topic guide a shorter online survey (appendix 2) was disseminated across London and nationally via number of mechanisms. The purpose of the online survey was to engage a wider group of professionals, to triangulate findings from semi-structured interviews and to obtain opinions from outside London. In addition an online twitter chat was conducted with an established



online community of learning disability nurses<sup>6</sup>. The questions used to guide this online discussion and a summary of the chat are in appendix 3.

To gather opinions from people with learning disability collaboration was undertaken with voluntary sector organisations with expertise in this area. Three different organisations helped with arranging three group discussions in addition to individual feedback via key workers. Participants included:

- women with learning disabilities who were currently or had recently been pregnant
- male and female parents who had a learning disability
- other people with learning disabilities in a 'spokesperson' role

The scope of these group discussions and individual feedback focused more narrowly on opinions of the easy guides and suggestions for improvements of these resources.

Simple thematic content analysis was undertaken on the notes taken from semi-structured interviews, group discussions and briefer telephone feedback and on email feedback and free comments in the online survey.

An assessment of the material in the easy guides was also undertaken using recognised tools to measure readability, presentation and health literacy, in line with tools suggested in a draft PHE screening publication evaluation toolkit.

## 5 Background on the easy guides

The 'Screening tests for you and your baby: easy guides' explain the screening tests offered during and after pregnancy for people with learning disabilities. The easy guides are adapted from the 'Screening tests for you and your baby' booklet<sup>7</sup>. The easy guides were developed by PHE, which held workshops with experts and users to refine the content<sup>8</sup>. The easy guides were launched on 10th February 2017.

There are eight separate sections in total – five covering antenatal tests and three covering newborn tests. A print run of the easy guides was not undertaken nationally. Health professionals can download and print off copies of the easy guides from gov.uk<sup>9</sup> to use when explaining screening tests offered during and after pregnancy to people with learning disabilities. Additional brief guidance to health professionals to print the guides in colour and single sided, to improve accessibility for people with learning disabilities, is stated on the website.

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<sup>6</sup> <http://www.wecomunities.org/tweet-chats/chat-details/4201>

<sup>7</sup> <https://www.gov.uk/government/publications/screening-tests-for-you-and-your-baby-description-in-brief>

<sup>8</sup> <https://phescreening.blog.gov.uk/2016/05/11/expert-group-will-ensure-easy-read-screening-information-is-fit-for-purpose/>

<sup>9</sup> <https://www.gov.uk/government/publications/screening-tests-for-you-and-your-baby-easy-guides>

Digital performance analysts in PHE finance and commercial directorate have used google analytics to provide data on how many people visited the 'Screening tests for you and your baby easy guides' pages from the launch of the guides on 10<sup>th</sup> February 2017 up until 30<sup>th</sup> September 2017, just before initial evaluation activities began.

A total of 2,749 people visited the main page between 10th February 2017 and 30th September 2017. There were 4,373 page views (each time the page is loaded by a user). There was an initial large peak in visits to the website around the launch date on 10<sup>th</sup> February, with more than 200 visitors on that day alone. Just after the launch, in the period 10<sup>th</sup> February to 28<sup>th</sup> February, there were 1847 page views. There were a further 817 page views in March 2017, with an average of more than 50 page views per day in this period. Activity tailed off after February and March 2017 to a fairly steady ongoing lower level. In the six months 1st April 2017 to 30<sup>th</sup> September 2017, there were an average of 9 page views a day.

## 6 Qualitative feedback

The objective of qualitative feedback was to gather in-depth comments on the easy guides and to explore further themes related to the provision of information in pregnancy to women with learning disabilities. Table 1 summarises the participants.

**Table 1 summary of participants and methods used for feedback**

Type of respondent	Settings/roles	Tools used	Number of participants (and dates)
Front line professional	Maternity professionals. Learning disability professionals, voluntary sector professionals	Semi-structured interviews, email feedback, analysis of free text within online survey and twitter chat.	66 (March to July 2018)
Policy, commissioning or strategy role (not front line professional)	NHS, Local Authority, Voluntary sector	Semi-structured interviews	5 (March to May 2018)
Person with learning disability	Women who are currently or have recently been pregnant, male and female parents of children of various ages, people with learning disabilities in 'spokesperson' role within advocacy organisations and in parent support group in voluntary sector organisation.	Group discussions, individual feedback via key worker	34 (March and April 2018)

## 6.1 Thematic analysis

A simple thematic analysis<sup>10</sup> identified overarching themes evident across all groups of participants, suggesting the easy guides are useful tools, but that health and other services could improve certain areas to ensure effective communication and provision of information to women with learning disabilities in pregnancy. Three key themes were evident in the feedback (table 2) with several sub themes.

**Table 2: key themes in qualitative feedback**

Theme	Sub themes
Utility of easy guides and other supporting materials.	Overall usefulness of easy guides. Content, format and language in easy guides. Awareness of easy guides. Other supporting products may enhance easy guides.
Staff confidence	Nervousness around discussions with people with learning disability Supporting personalised informed choice Concerns regards social services involvement
Wider system and service issues	Identification of women with learning disability Named leads, dedicated pathways and mandatory competency / training in learning disability Resources to put appropriate support in place

### Utility of easy guides and other supporting materials

#### *Overall usefulness of easy guides.*

Professionals who had used the easy guides in practice rated them highly as resources to help explain screening and there was generally positive feedback from people with learning disability that these were useful resources. People with learning disabilities are a diverse group and different groups of professionals were using the guides. Therefore, it may not be surprising that experience and opinion on whether the guides could be used independently by women without support, or if they needed a professional to explain the guides further, varied. Many professionals felt the easy guides would be useful with other groups of people, with a range of literacy or

<sup>10</sup> Methodology for thematic analysis informed by methods described by Judith Green and Nicki Thorogood in their book 'Qualitative Methods for Health Research'

information processing challenges and there was a feeling that the easy guides could be good for everyone as they are attractive and engaging.

*Content, format and language in easy guides.*

Overall the factual content appeared relevant and reliable, with both professionals and people with learning disabilities feeling the content was appropriate, helpful and informative. Very few factual corrections or queries were raised.

There was a feeling in some of the group discussions with people with learning disabilities that, in general within health literature, there should be more balanced information about the reality of having a baby with a condition or disability and living with disabilities. There was not a consensus on whether the easy guides were lacking in this respect.

Feedback was received on the easy guides language and use of certain terms that suggested language could be improved further. People with learning disabilities consistently commented on the use 'jargon' in places and felt this could be improved. This was a minor point not distracting from their overall positive feedback for the easy guides.

The format was largely felt to be appropriate, with some small improvements suggested. Overall the photos used in the guides were received positively, with a few suggestions in places such as photos could be more closely matched to the content of the text or the consistent use of the same people in the photos. In some places long sentences were commented on as needing simplification and some pages needing less text per picture.

Some front line professionals questioned the length of the easy guides and the time needed to go through them with people. Generally, however, this was not raised by people with learning disability themselves or by professionals who had used the guides in practice.

*Awareness of easy guides.*

Interviews revealed that many learning disability professionals and screening coordinators in London had seen the easy guides and circulated them to colleagues. However, not all front line staff playing a role in explaining or undertaking ANNB screening had seen them. Several people suggested that the easy guides, as they were such a good resource, should be made more available with comments such as placing them in waiting rooms, disseminating via channels wider than the PHE screening blog and ensuring voluntary sector support groups had access to them.

No professionals who participated were aware of any other information resources on ANNB screening specifically for people with learning disabilities; however, some general pregnancy /parenting materials from other sources are available. No one was using any of these alternative resources or recommending the use of other materials.

Overall the feeling was, to ensure quality, the health service should produce these materials centrally.

*Other supporting products may enhance easy guides.*

Whilst the easy guides received very positive feedback, all groups of participants felt additional supporting products would enhance the use of the easy guides and enhance information provision on ANNB screening to people with learning disabilities in general.

The most consistently suggested additional material was information in a video format, suggestions being a real life journey format through the ANNB screening pathway, a video summary of ANNB screening or video versions of sections of the easy guides. Video resources were also suggested for health professionals to aid their communication skills or confidence in this area. This suggestion fitted with wider suggestions of a PHE training module on ANNB screening and learning disability.

Other suggestions included enriching the webpage which the easy guides is housed on to have links to further materials to support staff in caring for women with learning disability or give further 'top tips' on using the easy guides.

### **Staff confidence**

*Nervousness around discussions with people with learning disability*

Many professionals interviewed expressed a lack of confidence in discussing issues around screening with people with learning disability. This seemed to stem from lack of familiarity, this group being a small cohort of the case load, and lack of training. The fact that screening has some complex concepts such as risks, chance, and consequence was often raised. This expressed lack of confidence did seem somewhat at odds with other commonly expressed views that complex case management, communicating choice to range of people, and individualised care are core skills of midwives and maternity services. It was not possible to reconcile these two points.

A particular nervousness was consistently expressed by front line maternity professionals regarding discussing screening for conditions which may lead to learning disability with a person who themselves has learning disability. Following on from this there was also uncertainty on how to counsel them on choices if a screening result indicated their baby may have a condition. There were various suggestions on how to overcome this particular nervousness. Training, education resources, and having a dedicated pathway or person who acts as a point of contact or reference, were all mentioned. Professionals within learning disability and voluntary sector support organisations acknowledged these were sensitive and difficult conversations for health professionals but believed it could be done well. They suggested anxiety is increased all around if a health professional seems unsure or nervous and it was important to be clear, direct and explain the purpose of tests.

They also felt they could play a role in producing communication training resources for other professionals.

#### *Supporting personalised informed choice*

Following on from the point above, many professionals expressed it was difficult to explain the implications of some screening tests to people, not exclusively people with learning disability. Some questioned whether, for women with more severe learning disabilities, they should even discuss screening and was screening appropriate in first place. The challenges of capacity, who should be consulted prior to screening and how to deal with the consequences of screening results for women with learning disabilities was raised as a real area of uncertainty for professionals.

How far informed choices were being made was debated. This was often coupled with a reflection by professionals on the fact most women 'just go along' with screening in pregnancy anyway and how far does any woman really understand the choices and consequences in the context of ANNB screening.

#### *Concerns regards social services involvement*

Concerns around social services involvement also seemed to fit into staff confidence. While health professionals were well aware of their duties and processes, and most appeared to have experience of raising safeguarding concerns, there was a sense of lack of confidence around having these difficult conversations with someone with learning disability.

For women with learning disability concern of social service involvement was frequently raised by professionals as a potential barrier to asking questions and making informed choices as they may not wish to raise concerns about their understanding and risk a referral. The process of social services involvement was seen as difficult and stressful by all sides. Whilst the starting point for all engagement with participants was information provision on screening very early on in conversations concerns around safeguarding and the most extreme implications of social services involvement and baby removal were raised. This suggests these concerns are to the fore in interactions with women with learning disability when they are pregnant.

### **Wider system and service issues**

#### *Identification of women with learning disability*

Most maternity units seemed to only have one or two women with a formal diagnosis of learning disability each year, with the maximum stated in this evaluation as 5 in a year. However, frequently mentioned by professionals was that those with a formal diagnosis of learning disability were the 'tip of an ice berg' of women who may have difficulties processing and understanding information meaning they would benefit from additional support to understand screening. Identification of women with

learning disability, or other information support needs, was felt by most to be difficult, especially given the fact many who would benefit do not have formal diagnoses and are not on a learning disability register, or flagged in the hospital systems or notes. A recurrent theme was that people themselves may not recognise they have a learning disability and professionals felt in a difficult position of bringing this up and offering appropriate support without labelling or offending someone. This was particularly mentioned in the context of then using an easy guide with women. Issues around restriction of funding and resources to those with a formal diagnosis of learning disability was mentioned, with the feeling this missed a lot of women and missed opportunities to improve health and well-being.

A tension for women was raised by several, in both health and other settings, of admitting difficulties understanding, getting a diagnosis and onto a register, (to enable reasonable adjustments) and the considerable fear, especially in the context of maternity services, of having a baby removed. This concern over safeguarding process and social services involvement was seen by many professionals as a real barrier to accessing appropriate support. For women with learning disabilities previous experience of safeguarding processes and referrals to social services in pregnancy was felt to impact on willingness to engage in subsequent pregnancies.

The importance of early flagging and referral for support was frequently mentioned alongside the difficulties in ensuring this happened. For those with a known diagnosis, flagged right at the beginning of pregnancy there was a feeling that it was easier to get appropriate additional support in place. Professionals gave examples of good practice in services of hospital passports, flagging of notes, and learning disability registers. There was a feeling that if a woman has got these in place they worked well, but not all women who would benefit are included in these systems. In general people did seem to think those with significant additional needs, without a formal diagnosis, were often picked up early in care by midwives. One theme in the feedback was that women and their family won't necessarily flag issues unless professionals ask questions and the onus is on professionals to make good assessments to pick up additional needs.

*Named leads, dedicated pathways and mandatory competency / training in learning disability*

There was a lack of consensus around the need for named leads or pathways for learning disability within ANNB screening, or maternity service more widely, and over the need for mandatory competencies and training for all in this area. There appeared not just to be differences in views but a tension with a feeling that dealing with more complex cases, communicating choice to range of people, and individualised care were core skills and professionals should ensure tailored care is provided for all women, including those with learning disability – whether formally diagnosed or not. Some drew the conclusion from this that maybe dedicated leads,

training and pathways were not needed but at the same time acknowledged at present women who may benefit from additional support may not be getting this.

Those in favour of a dedicated pathway or person who acts as a point of contact or reference raised it is not easy as a lone professional to find the appropriate services or resources to provide tailored care; hence the need for a system to ensure support can be put in place more easily. Those less sure of the merits highlighted there is a risk of health professionals making assumptions about people and their needs on the basis of a label or diagnosis, that additional needs or adjustments are not always thought of for less visible needs and many who need additional support may not have a formal diagnosis and be flagged for a pathway or picked up by a named contact /reference person. They were more in favour of ensuring individualised assessment and care for all.

Training was raised; with some feeling learning disability is currently 'squeezed into safeguarding or equality and diversity training' and not given the attention it needs. The tension between this and constraints on staff time and resources to make learning disability another mandatory requirement were frequently mentioned, with no clear conclusion. Where people discussed locally provided in-depth training it was felt to have been beneficial to practice, but constraints meant this training was infrequent and, due to staff turnover, its impact was diluted over time.

Many participants highlighted that there was often a significant cross over between learning disability and a range of other issues; most strongly highlighted was safeguarding, but also mental health, substance use, and migrant health. Many mentioned that women would often be flagged or referred for more support under one of these labels and they would feel there was an element of learning disability, typically which may not be formally diagnosed. Professionals highlighted there were layers of problems and ongoing health needs for people with learning disability and when they were seen in maternity services they may not always be accessing all the required support and advocacy.

Participants mentioned there were lead or specialised staff or pathways for other focal areas of additional support, outlined above and in some units these areas had dedicated contact or reference people or pathways but learning disability did not. In line with feedback above there were mixed views, given the crossover of issues, as to whether the current configuration of specialised or lead staff and pathways and support were optimal, or if learning disability was not given the due attention needed. A clear theme in feedback was that safeguarding was the biggest priority and women would be flagged and referred down that route as soon as any concerns were raised.

#### *Resources to put appropriate support in place*

Connected with the themes on safeguarding mentioned above, many professionals raised the issue of resource constraint and how, in an ideal world, the system should be able to support all women, but the reality was of limited resources. The more



extreme end of the spectrum, with removal of a baby, seemed to be present in every professional's mind when discussing learning disability and screening and aligned with the fact that safeguarding was frequently mentioned as a key driver or concern.

Given the reality of time and capacity constraints how to support women effectively as professionals was frequently raised. Some key facilitators to good information provision and care raised were; early identification and planning, support from a wide range of professionals, considering information and support for the family and other key people and tailoring the approach to the women, her level of understanding and her context of support. In terms of providing information on screening, there was a feeling professionals needed to be much more open in discussions, and not skirt around difficult issues and that easy guides or other easy read materials are not used in place of a conversation, but to support a conversation. Examples of other adjustments that could be put in place in services included bleeper systems for blood tests, so women did not have to wait in crowded waiting rooms, arranging bespoke maternity tours and antenatal classes. Some raised, given the length and intensity of contact over pregnancy, it provided a good opportunity to engage women with learning disability, especially if undiagnosed, and put things in place to improve her health and circumstances more generally.

Alongside professional support, family support was often raised. Participants highlighted they saw a mixed caseload, some with good family networks and some not, some in supportive relationships, some not, some having been subject to exploitation or abuse. It was felt partners or family would often have a range of other issues, including learning disability or additional support needs. The role of fathers, their involvement or assumptions about them and their level of understanding or interest in screening were raised. Professionals noted many times women would be alone in appointments, or have an advocate with them and not a partner or family member. Recurrently it was mentioned that being accompanied in appointments and when given important information alleviates a lot of anxiety. Professionals alluded to that fact that many women are already aware scans and blood tests take place in pregnancy, although they may not be aware of the screening purpose of these, and often use their own contacts in the community to provide information. Professionals then commented they spent time correcting incorrect assumptions, rather than giving information on what is available and why.

A number of system issues at local or national level were raised in the course of interviews with professionals. There was a general feeling that services within the NHS were improving in their awareness and ability to make reasonable adjustments for people with learning disability, but that this was variable and there was more to be done. People with learning disability themselves echoed this. Connected with this, there was variation in the level of specialist learning disability support to ANNB screening and maternity services between units in London.

Alongside the theme highlighted above on the value of pathways and training for learning disability was much discussion on supporting tools for professionals. Many were advocates for the development of local or national toolkits around learning disability and ANNB screening or maternity more generally. There was consensus around the fact there was 'no point in reinventing the wheel' and identifying an appropriate body, be it PHE, NHS England or a professional body such as the nursing and midwifery council, to gather, collate resources already developed, and make readily available was a frequent suggestion. Following on from this were suggestions of an analysis of any gaps and new resources created as needed. There was acknowledgement the current resource climate made this difficult, especially at a local level, but a general feeling this was important work that is currently missing.

## 6.2 Specific feedback on the easy guides from people with learning disabilities.

More detailed feedback on the easy guides from people with learning disabilities is tabulated below (table 3).

**Table 3: summary of feedback from people with learning disability**

Key feedback	More detail on feedback	Comments on consistency of feedback
Easy guides are helpful	Easy guides aided understanding and reduced anxiety by explaining what tests would happen and why.  Photos from health care settings, showing process of screening particularly well received as helping understanding and reducing anxiety.	Consistent, positive feedback across groups with improvements and comments noted below
Length and format of guides is generally good	Division into eight easy guides, length of each easy guide, format within each guide and presentation of material generally felt to be good	Consistent feedback across groups that format of easy guides good with improvements and comments noted below
There is trust in NHS produced resources	Trust in NHS labelled documents as feeling one can know these will be correct. Prefer these over other sources for health information.	Trust in NHS sources raised strongly by one group and other groups agreed good to have health service produce these. Generally trusted health service sources over others.
Small improvements to guides could be made	Main negative comments were related to use of 'jargon' and words felt to be medical or technical terms without explanation.	Fairly consistent comments on photos and diagrams that were clearer than others. Very consistent feedback on use of jargon/technical terms

Classification: Official

	<p>Improvements suggested to the specificity of some photos to the text / content and clarity of diagrams.</p> <p>Some formatting suggestions, mainly around amount of text per photo in some places.</p>	
<p>Additional supporting materials, especially video, would be beneficial</p>	<p>Consideration of a summary, either easy guide or video, to give an introduction to screening in pregnancy in general before the eight easy guide chapters.</p> <p>Suggestions for a variety of video formats e.g. short clips of procedures or explaining certain condition, a Vlog depicting a journey through screening or video versions of the easy guides.</p>	<p>Video materials raised consistently, and without prompting, by all groups</p>
<p>Generally people needed support to understand the easy guides</p>	<p>Some women may be able to understand the easy guides without support, but generally support needed and feeling that looking at the photos in isolation, without support, does not explain adequately the information intended.</p>	<p>Varied somewhat between groups depending on level of experience and literacy of individuals</p>
<p>User testing of easy guides and other materials, with the intended audience, is important</p>	<p>Testing materials with people with learning disability is important to ensure they meet expectations and needs.</p> <p>Groups / organisations involved in feedback on these user guides expressed willingness to be engaged in future reviews.</p>	<p>Consistently highlighted by people with learning disabilities and the organisations that support them</p>

Feedback from group discussions and individuals via their key workers can be grouped into seven key areas:

- Easy guides are helpful

The easy guides were felt to be helpful, useful and aided understanding. It seemed it was particularly felt to be helpful in the fact it reduced anxiety, by knowing what would happen throughout screening and why. Groups really liked the use of photos showing what would happen and seem to find this the most helpful aspect. The pictures in healthcare settings, as in showing actual scan taking place, were

particularly well received and were felt to aid understanding the most and reduce fear of unknown. There was a general dislike expressed of materials that contained cartoons or line diagrams. Some said that these were 'childish' or more difficult to understand.

- Length and format of guides is generally good

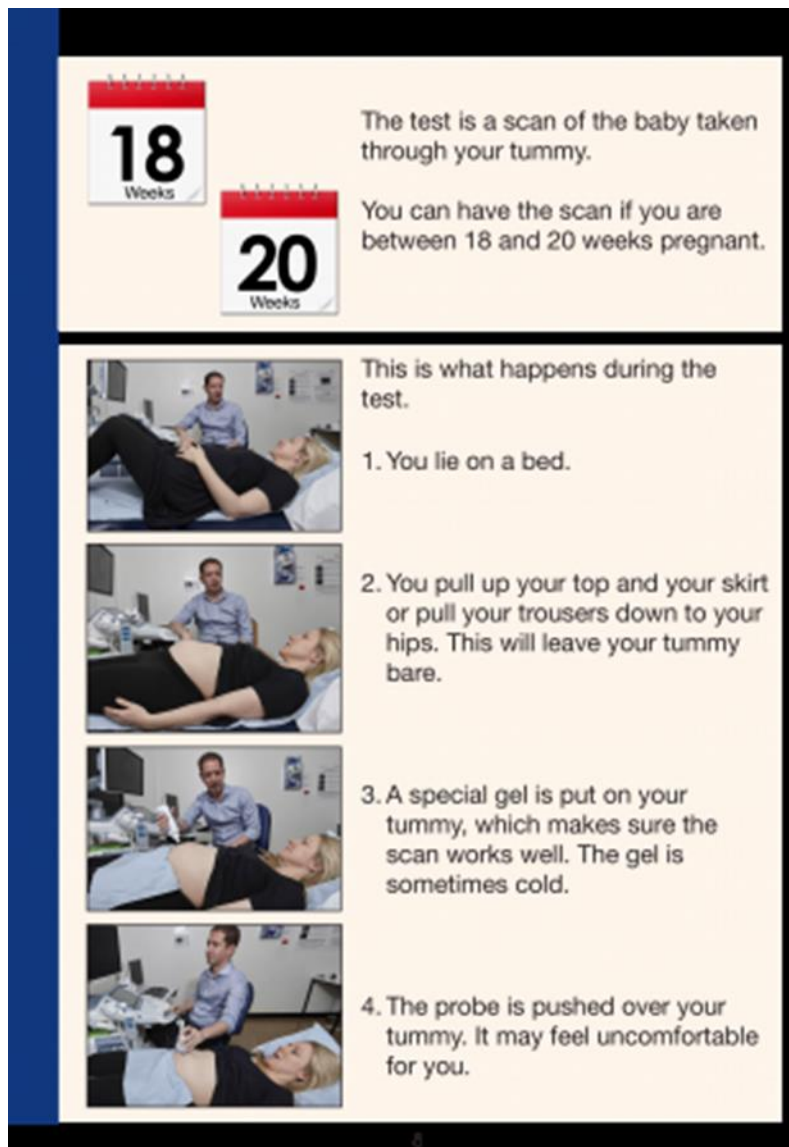
The fact there were eight different leaflets to cover ANNB screening was generally felt to be acceptable, with comments that it was better to have all the information available and better for this to be in smaller sub sections.

Some groups commented that 3 – 4 pages is normally a good length for a leaflet, but acknowledged this was quite a complex area and leaflets may need to be longer, and should not leave information out. In general it seemed the length of the easy guides was fine, especially if someone was going through it with you.

The lay out, with the breakdown into sections of text by each photo, was felt to be done well, spaced out nicely and the boxes around each sub section were good. The comments received were that people with learning disability often find it difficult to concentrate and this 'chunking' helps. The material looked interesting and attractive (with colour use) so people wanted to engage with it. The font size was commented to be good and generally the text to each photo appropriate, although with suggestions for improvements noted in some places.

Figure 1 below is an example of an easy guide page which was consistently mentioned as being good and helpful, as the text relates clearly to picture, the picture shows exactly what happens in the course of the screening test and there is a limited amount of text per picture.

**Figure 1: Example of easy guide page receiving good feedback**



- There is trust in NHS produced resources

Across groups there was an appreciation that the health service had produced these easy guides and a trust in NHS labelled documents expressed, as people felt they could be confident the content within them would be correct. Generally people expressed the view that they preferred NHS branded material over other sources for health information.

- Small improvements to guides could be made

One of the main negative comments on the guides was the feeling that they used 'jargon' or 'technical/medical terms' and these terms needed further explanation where they first occurred or simpler words needed to be used. Jargon / technical words included; condition names (such as thalassaemia, hepatitis, diabetes) procedure names, (such as amniocentesis) or other terms (such as 'screening' or 'diagnostic'). The presence of these words especially seemed to be a barrier to engaging with the easy guides when they appeared on the title page. There was a

feeling the terms on the title page needed to be explained straight away or a simpler title put. Certain sections of the easy guides were highlighted as having more 'jargon' and being more difficult to understand – such as the sections around specific conditions. Here some groups commented that, rather than trying to explain details in the guide, a link to a video would be more understandable. Groups generally thought that proper medical terms should not be completely removed though, as it is important to know this as well, in case people use this term with you.

Improvements were also suggested on some of the photos and diagrams. Some of the photos were felt to be non-specific to the intended content that accompanied it. There was then some confusion when reusing that photo for different text or different points. Some participants felt the women in the photos 'don't look like me ... looks well to do' and not identifying with the women seemed to be a barrier to taking the information in. Some participants felt it was confusing when the people in the photo sequence changed, as they had seen it as explaining one woman's journey through screening, or when there was inconsistency in the apparent ethnic background of parents and a baby in the same easy guide. In places there was felt to be too much text, or too many different points of information per photo.

All groups found the genetic diagrams in some easy guides confusing and, even after quite a lot of support to understand the concepts, had questions which strayed from the purpose of the screening tests. Most of these were able to be dealt with when people were supported through leaflet by a professional, but even with this some confusion was left for some people. There was a feeling that mentioning genes and carriers made things unnecessarily complicated, with one participant commenting 'I Just want to know how affects me and my baby – not the background'.

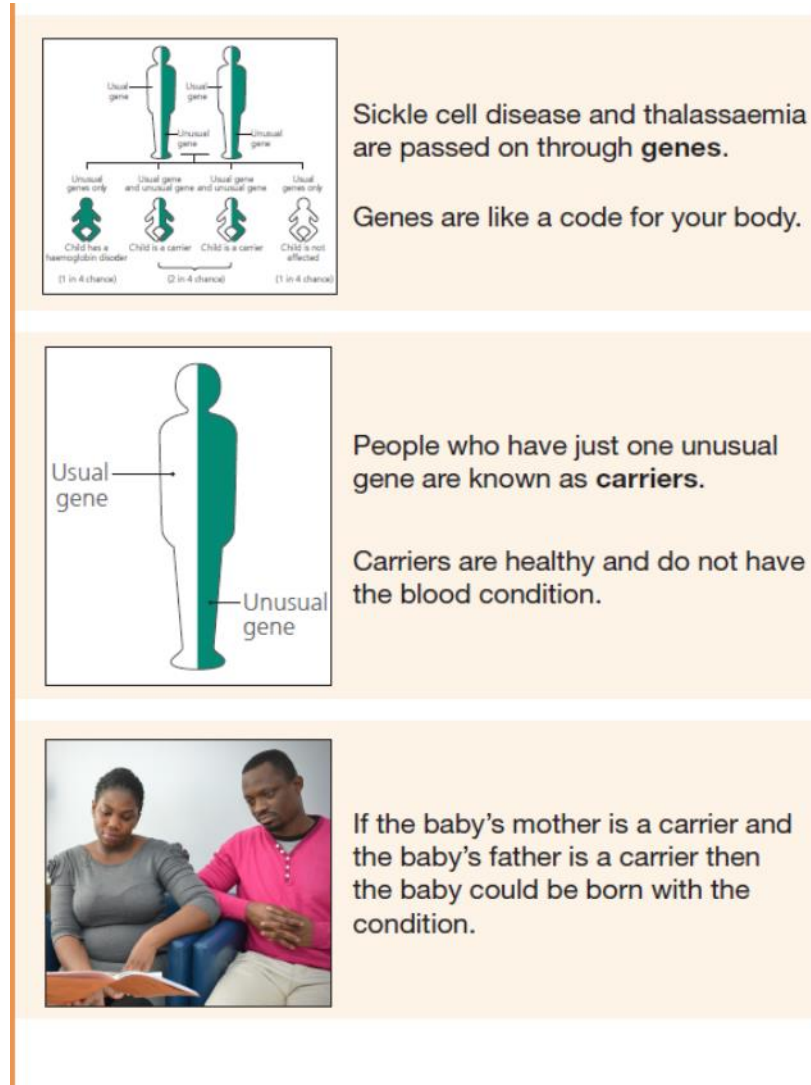
Whilst mostly positive, there were some mixed views on the indexing and use of colour coding, and whether this helped to navigate the easy guides or not. The system was generally understood by people, although one group commented on the accessibility to those who may be colour blind. One group suggested moving the page numbers on the index page across to same side as the colour code and to add a picture relevant to the chapter topic, so on quick scan people can see what the guide is about and navigate to correct part in a variety of ways including colour, number and picture.

As an overall reflection on the way the content of the guides is presented there was a feeling among some that the order in which information is presented in each leaflet is slightly wrong. There was a feeling that information on the condition and why there is a need to be tested for them in pregnancy needs to be presented first before going into anything else, in order to gain the readers understanding on why they should bother with either reading the easy guide or understanding / having the test.

Figure 2 below is an example of a page of an easy guide which was found to be less clear and where several suggestions to improve were made. The diagrams were not understood, and even with support were found confusing 'Is half of my body good

and half bad'. The word 'Genes' was considered to be jargon, even with explanation of 'code'. The photo of the couple looking at book was felt to be non-specific and not impart any information with one comment being they 'could be discussing anything'.

**Figure 2: Example of page attracting suggestions for improvement**



Sickle cell disease and thalassaemia are passed on through genes.

Genes are like a code for your body.

People who have just one unusual gene are known as **carriers**.

Carriers are healthy and do not have the blood condition.

If the baby's mother is a carrier and the baby's father is a carrier then the baby could be born with the condition.

- Additional supporting materials, especially video, would be beneficial

There was a general consensus from the feedback that a more general introduction or summary explanation of what screening in pregnancy is, and why it takes place, would be helpful to aid understanding of the specific easy guide chapters. This could either take the form of another easy guide or be a video format.

The subject of augmenting the easy guides as they currently stand with video content was consistently raised. Suggestions were made for a variety of video formats including short clips outlining procedures or explaining certain conditions, a 'Vlog' depicting a journey through screening or what it is like to have a condition or video versions of the easy guides. There was a feeling that videos had benefits as they could be watched repeatedly without additional support to reinforce the information or

if anything was forgotten. There was a feeling that seeing a video of a real women going through the screening stages and talking about it would really reduce any anxiety around screening.

A consistent suggestion was to embed links in the easy guides to videos or other resources. One participant sums up the general consensus on people use of the internet 'Everyone has smart phone and googles things'. This was coupled with the feeling that there was a need to ensure content used to understand further was correct and it would be better for the easy guides to direct people proactively to properly vetted sources.

There was a fairly consistent feeling that, with a general introductory guide or video and the use of more video links, each easy guide could focus more on the choices available to women and the pros and cons of screening.

Questions were asked by groups as to whether it would be feasible to produce other formats such as easy read braille and easy read in other languages.

- Generally people needed support to understand the easy guides

Some feedback indicated that women with mild learning disability could mostly understand the easy guides without the support of a professional providing additional explanation, however mostly people seemed to feel additional support was needed to understand all of the information presented. Those who had a lower level of reading skills found the photos very helpful, and could generally follow the gist of the guide, but most felt if just looking at photos in isolation it was not always clear what the intended message was and information would be missed. The support needed to understand the guide varied depending on peoples experience with maternity services, and health care in general, and their learning disability and reading skills.

- User testing of easy guides, and other materials, with the intended audience is important

All groups, and the organisations that supported them, brought up points around the importance of testing materials with people with learning disability to ensure they meet expectations and needs on both the side of the person wishing to impart the information and the intended audience.

All groups brought up examples of 'good' and 'bad' informational leaflets on other topics, commenting they could have easily been improved if people with learning disabilities had been consulted. Professionals within organisations who support people with learning disability also highlighted that they themselves sometimes find it difficult to know what will work or not, pitch things wrongly at times and really rely on user feedback and revision of materials to ensure their utility.

All organisations involved in facilitating feedback for people with learning disabilities, and many of the people with learning disabilities themselves, expressed a willingness to be engaged in reviewing and commenting on future drafts and testing any additional materials.



## 6.3 Conclusions

In terms of the wider context in London, qualitative feedback indicated there were low numbers of women with a formal diagnosis of learning disability per maternity unit each year – in most cases one or two with the maximum stated in this evaluation as 5 in a year. However, this was felt to be the ‘tip of an iceberg’ of women who may have a degree of learning disability which had not been formally diagnosed or who needed additional support with information provision for a variety of reasons. An overlap between learning disability and a variety of other issues, such as safeguarding, mental health and migrant health, was consistently apparent in feedback across London. Across the participants in London there was variation in pre-existing awareness of the easy guides, training and confidence in discussing with people with learning disabilities and how services were set up with regards to pathways or lead professionals for pregnant women with learning disability. Feedback suggests the easy guides are well received and a useful tool but that health and other services could improve certain areas to ensure efficient communication and provision of information to women with learning disabilities in pregnancy.

In terms of feedback from parents with learning disabilities, it appears the easy guides aid understanding of ANNB screening. Most people required some support to understand the content of the easy guides and they were not a standalone resource. A number of suggestions for minor changes were gathered, which included improvements to terminology, photos and formatting. These did not distract from the overall positive feedback. The addition of video resources was consistently suggested. Perhaps the overall feedback from parents with learning disability could be summarised in the words of one participant:

‘It’s good, but have videos, then make it shorter and have simpler words’  
(Quote from parent with learning disability in group discussion)

## 7 Online Survey

An invitation to complete the online survey was disseminated across London, and nationally, via a number of mechanisms including emails to networks of ANNB screening providers/professionals in London, social media in the form of NHS England (London) and PHE blogs, and highlighting the survey in face to face ANNB screening meetings in London.

### 7.1 About the people who responded

The online survey had 44 respondents, spread across all PHE regions except the West Midlands, as follows:

- North West 13
- Yorkshire & Humber 8

- East of England 7
- South West 5
- South East 4
- London 4
- East Midlands 1
- North East 1

The majority of respondents were either antenatal and new born screening professionals involved in commissioning or delivery of ANNB screening programmes (21 people, 48%) or midwives, obstetricians or other maternity health professional involved in clinical care of pregnant women (14 people, 32%).

Over half, 25 people, said they had direct experience of providing women with learning disabilities with information on antenatal and new born screening.

The majority (31 people) had had no training in providing information to women with learning disabilities. 13 people had had general training on working with people with learning disabilities. No one reported having received specific training in communicating in the context of maternity/ antenatal and new born screening.

There was variation in how equipped people felt to communicate antenatal and new born screening information, options and support decision making with women with learning disabilities. The vast majority were either moderately (22 people) or somewhat (13 people) equipped. Seven people felt well equipped and two people not at all equipped.

## **7.2 Awareness of the easy guides**

Almost two thirds of people (28 people) were aware of the PHE 'Screening tests for you and your baby' easy guides before being asked to complete the survey. The most common way people had found out about the easy guides was via the PHE screening blog (19 responses). This was followed by local communication either formally or informally (6 responses).

Only 4 respondents stated they had received any formal or informal training or support locally to use the easy guides.

## **7.3 Experience of those who had used the easy guides in practice**

Eleven respondents stated they had used screening tests for you and your baby' easy guides as part of their work. These respondents were asked some further questions on their experiences with the easy guides. The majority of respondents said they had used the guides only once or twice (10 responses). Eight respondents stated they had used the easy guides with women with learning disabilities themselves and a further 2 respondents stated they had used it with carers or supporters of women with learning disabilities. The majority used the guides by

printing off and using a hard copy (9 responses) and not by using the guides online on a device (1 response).

Those who had used the easy guides were asked if they went through the easy guides in the consultation. Around half of respondents had gone through all of any relevant sections (4 responses) and around half had gone through parts of relevant sections (5 responses). Eight respondents had given a hard copy to women to take home and a further one respondent had given a hard copy to a carer or supporter. Two out of 11 respondents had given the web link to a women or carer/supporter.

#### 7.4 Feedback on the easy guides

All respondents, whether they had used the easy guides in practice or not, were asked their opinion of how well the easy guides performs in the areas of:

- Accessibility (content readable and understandable and provided in the correct format)
- Authenticity (information reliable and honest)
- Balance (is the content biased? Is the purpose of it clear?)
- Impact (does the content affect the reader's opinions or feelings, does the content of the easy read make it easier to explain for the professional and easier to understand for the user?)
- Usability (does the content help the reader make a decision?)

Between 31 and 33 responses were received on each aspect of the guides. The easy guides were rated excellent or good in all of these areas by the majority of respondents. The accessibility and authenticity was rated excellent or good by over 80% of respondents, the balance rated excellent or good by 75% and the impact and usability rated excellent or good by around 60% of respondents. Whilst overall still rated by the majority as excellent or good, the feedback appears more neutral about the impact and usability than the other aspects of the guides.

**Table 4: Summary of easy guides ratings from online survey**

Rating	Accessibility - Percentage of responses (total = 33)	Authenticity - Percentage of responses (total = 33)	Balance - Percentage of responses (total = 33)	Impact - Percentage of responses (total = 31)	Usability - Percentage of responses (total = 31)
Excellent	24%	33%	30%	19%	16%
Good	58%	55%	45%	45%	42%
Neutral	12%	9%	21%	26%	26%
Fair	6%	0%	3%	10%	13%
Poor	0%	3%	0%	0%	3%

Ten responses were received for suggestions for improvements to the easy guides, these included small revisions to the use of language, considerations around

shortening text and revising photos and providing more information in some more specialised areas.

In addition wider suggestions on improving information provision included improving access to the guides rather than the gov.uk website, providing video resources and having more time in antenatal appointments to discuss information.

## **7.5 Conclusions**

Whilst this survey's findings have some limitations, namely the small number of self selecting respondents, it does provide some valuable insights. Most of those who responded were front line maternity staff and those in working in ANNB screening across the country and over half had practical experience providing women with learning disabilities with information on antenatal and new born screening. There was a low level formal training and generally a feeling of being either moderately or somewhat equipped in this area.

Awareness of the easy guides was good in this group, with two thirds having seen the guides before becoming aware of the survey. However, the representativeness of this to front line staff in general may be limited due to the small sample and self-selection of respondents.

Experience of using the guides was lower and only the minority of respondents had used the guides with women and most of these only used them once or twice. Those who had used the guides generally appeared to have used them as intended, printing out in hard copy and going through them in an in consultation with women. The majority had also given a copy to take home.

Feedback on the easy guides was generally good. It may be that people rate the impact and usability more neutrally than the accessibility, authenticity and balance. Suggestions for improvements that could be considered going forward included small revisions to the text and photos, improving ease of access to the guides and considering additional materials in other formats such as video.

## **8 Other tools to evaluate the easy guides**

PHE Screening has in draft an evaluation toolkit which outlines a consecutive 5-step procedure to evaluate all public-facing publications, not just easy guides. The 5 steps proposed are:

1. Review the feedback via various channels, such as GOV.UK feedback explorer.
2. Perform a readability assessment.
3. Perform the Suitability Assessment of Materials instrument.

4. Perform the DISCERN assessment.<sup>11</sup>
5. Conduct iterative consumer test in the target population.

This evaluation has included processes similar to steps 1 and 5, namely the online survey, feedback from interviews with professionals and engagement with people with learning disabilities. As part of evaluation the easy guides have been reviewed against readability assessments and the suitability Assessment of Materials instrument (steps 2 and 3). Step 4, the DISCERN tool, has been omitted due to uncertainty regards its applicability to the easy guide format.

## 8.1 Readability Assessment

A readability assessment indicates the number of years of education that a person needs to be able to understand the text easily on the first reading. The text from each of the easy guides was run through two online readability websites<sup>12</sup> which used the Simplified Measure of Gobbledygook (SMOG) and other indexes to give an estimate of school level (and hence approximate age) needed to understand each guide. In order of simplicity by school grade, least schooling to most, the easy guides are in table 5 below, with their average US grade score, based on multiple readability tools.

There was some variability in the estimated school grades between online websites and indices used, with the SMOG producing a higher estimate than the average of other indices. Using SMOG the US grade ranged from grade 6, which roughly equates to English school year 7 /age 11 – 12 years to US grade 10, which roughly equates to English school year 11 /age 15 – 16 years. Using an average of other indices the US grade ranged from grade 4, which roughly equates to English school year 5 /age 9 – 10 years to US grade 8, which roughly equates to English school year 9 /age 13 – 14 years. A full table of readability scores from different indices is in the appendix.

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<sup>11</sup> For more information about the DISCERN instrument to help judge the quality of written information about treatment choices see [http://www.discern.org.uk/discern\\_instrument.php](http://www.discern.org.uk/discern_instrument.php)

<sup>12</sup> Online tools used were [https://www.online-utility.org/english/readability\\_test\\_and\\_improve.jsp](https://www.online-utility.org/english/readability_test_and_improve.jsp) and <https://readable.io/text/>

**Table 5: Summary of average readability assessment US school grade/ age equivalents**

Easy guide	Average US Grade score from online tool at readable.io	Approx age equivalent of average US grade score <sup>13</sup>
Screening for problems with the baby's body	U.S. grade level 4.4	9 to 10 years
Looking at your baby's hearing	U.S. grade level 4.6	9 to 10 years
Screening for eye problems for pregnant women with diabetes	U.S. grade level 5	10 to 11 years
Looking at your baby's heart, eyes, hips and balls (testes)	U.S. grade level 5.1	10 to 11 years
Screening for Down's syndrome, Edwards' syndrome and Patau's syndrome	U.S. grade level 6.2	11 to 12 years
Blood spot tests	U.S. grade level 6.2	11 to 12 years
Screening for hepatitis B, HIV and syphilis	U.S. grade level 6.7	11 to 12 years
Screening for sickle cell disease and thalassaemia	U.S. grade level 8.8	13 to 14 years

## 8.2 Suitability Assessment of Materials (SAM)

Grade-level readability is one of many factors that contributes to the overall readability of materials. Even materials written on a low grade level may be difficult to comprehend if proper attention is not also paid to organisation, layout, and design. The Suitability Assessment of Materials (SAM)<sup>14</sup>, offers a tool for assessing texts which moves beyond readability assessments and considers other important aspects of materials - such as organisation, format, design and culture - that may ease or hinder reading, comprehension and use. The Suitability Assessment of Materials instrument rates materials in 6 areas:

- Content
- Literacy demand
- Graphics
- Layout and type
- Learning stimulation and motivation
- Cultural appropriateness

A score is achieved for the materials out of a possible maximum of 44 and giving a SAM percentage score. A typical score is 34/44 or 77%.

The easy guides were assessed against the SAM instrument with the scores shown in table 6. All easy guides scored poorly against the criteria for not including a summary or review and for limited use of interaction. Three easy guides scored lower than 77%, Screening for sickle cell disease and thalassaemia (at 68%), Screening for

<sup>13</sup> Approximate age taken from <http://www.free-for-kids.com/uk-us-education-systems.shtml>

<sup>14</sup> The SAM Suitability of Materials Assessment Method was developed by Doak, Doak and Root in 1993 and published in the book: Teaching Patients with Low Literacy Skills, Lippincott, Williams & Wilkins, 1996

Down's syndrome, Edwards' syndrome and Patau's syndrome and Blood spot tests (both at 72.5%). These easy guides also sat among the guides with higher school grade levels.

**Table 6: SAM scores for easy guides**

Easy guide	SAM percent score (total score/ total possible score)	Areas scoring not suitable (0)
Screening for hepatitis B, HIV and syphilis	77.5% (31/40)	Summary or review included Interaction used
Screening for sickle cell disease and thalassaemia	68% (30/44)	Summary or review included Interaction used
Screening for Down's syndrome, Edwards' syndrome and Patau's syndrome	72.5% (29/40)	Summary or review included Interaction used
Screening for problems with the baby's body	90% (36/40)	Summary or review included Interaction used
Screening for eye problems for pregnant women with diabetes	85% (34/40)	Summary or review included Interaction used
Looking at your baby's heart, eyes, hips and balls (testes)	90% (36/40)	Summary or review included Interaction used
Looking at your baby's hearing	85% (34/40)	Summary or review included Interaction used
Blood spot tests	72.5% (29/40)	Summary or review included Interaction used

The readability assessments of the easy guides, and the initial SAM review by one reviewer, would seem to support some of the qualitative feedback received around simplification of text and considerations around the use of technical terms / jargon. It would also seem to support the use of more interactive media (video) to engage and reinforce information as per the qualitative feedback.

## **9 Conclusions, recommendations and further work**

### **9.1 Improvements to the easy guides and awareness of this resource**

Minor revisions to improve the guides have consistently been suggested throughout the qualitative feedback. These suggestions have been received in the context of positive feedback for the guides, suggesting they are a good resource as they stand. It would therefore seem ***review and revision of the content and format of easy guides can take place when natural opportunities arise***, such as with the upcoming revisions to include Non-Invasive Prenatal Testing (NIPT), or as and when the PHE screening team have capacity.

The primary revisions which could be considered are:

- The choice of **photos used and their specificity to content of text**
- A further **break down in the amount of text per photo**
- Further **simplification of text** and especially revision where possible of the use of **technical terms / jargon**

**Links made during this evaluation** with voluntary sector organisations and parents with learning disability **should be maintained to facilitate continued engagement of parents with learning disability in the review of easy guide materials.** In addition learning disability professionals via the online **@ WeLDnurses community have expressed willingness to support** review of current materials and development of new products. As an output of this evaluation key contacts will be shared with PHE colleagues for them to engage as they continue to revise the materials.

Awareness and use of this resource appeared variable across London, and among national online survey respondents a third had not seen the resource. Therefore, **further work locally and nationally should be undertaken to raise the profile of this resource** and make sure those front line staff who would benefit from having it to support women know how to access it.

As an output of this evaluation a **PHE screening blog will** be produced to **share the findings** but also to **reinforce dissemination and use of the easy guides nationally.** At local level in **London engagement** started in this evaluation **via ANNB screening boards should be continued** to share findings and continue to widen the group of professionals using and sharing the easy guides. Other dissemination activities are also recommended below.

## **9.2 Additional resources for PHE screening to consider – in partnership with others as appropriate**

**Very consistent feedback has been received from professionals and people with learning disabilities regarding production of video content** to support the easy guides. A number of forms of video content have been suggested that include:

- Video resources for Health professionals
  - Examples including video resources where parents with learning disabilities talk about their experiences, or how they would like to be supported. This was suggested as being helpful in addressing the confidence and training issues highlighted.
- Videos resources for people with learning disabilities
  - Suggestions including converting the whole easy guide into video format or creating shorter video sections on particularly complex aspects e.g. explaining conditions, diagnostics tests and implications

The suggestions around video resources, coupled with consistent suggestions that an introductory or overview easy guide on the whole ANNB pathway would be useful,



leads to a recommendation that ***an easy guide video giving an overview of ANNB screening pathway*** may be the ***first material to consider producing***. As in review of the current easy guides ***engaging people with learning disability and relevant professionals in the development of any new resource is key*** and the key contacts mentioned above under reviewing the current materials should be utilised.

A further summary of the findings of this evaluation relevant to video resources will be produced to aid discussions between PHE screening and NHS.UK.

The qualitative feedback suggests professionals would value more information and training resources, including linkages to other materials from the easy guides web page, again addressing confidence and training issues identified. As a first step, ***producing a 'top tips' type document to support professionals similar to 'Supporting women with learning disabilities to access cervical screening'***<sup>15</sup> would seem a reasonable way forward, and within PHE's remit.

A further summary of what may be useful to include in such a document, based on the findings of this evaluation and case studies of good practice, and key contacts for PHE screening to work with will be produced to aid PHE screening in developing this.

### **9.3 Wider system change at London and national level**

This evaluation highlighted issues, and possible improvements, for supporting women with learning disabilities within ANNB screening. Many of these are difficult to separate from wider maternity service and system issues locally and nationally. Areas for consideration include maternity unit pathways for learning disabilities, having a lead or person who acts as a point of contact or reference for learning disabilities, local and national training and competencies and resource sharing at local and national level.

There is a ***need to take these issues forward within wider learning disability and maternity service / systems discussions in appropriate forums in London***.

There are a variety of groups and work streams which already overlap the issues raised by this evaluation. Further work to map local and national services within ANNB/maternity, training tools and resources and to identify gaps would be beneficial.

Recommended as initial actions from this evaluation are:

- ***NHS England (London) ANNB team to take evaluation findings to the London maternity transformation board*** for discussion and formulation of further action
- Consultant in Public Health for Antenatal and Newborn Screening within NHS England (London) to ***present findings in appropriate forum with National***

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<sup>15</sup> <https://www.gov.uk/government/publications/cervical-screening-supporting-women-with-learning-disabilities/supporting-women-with-learning-disabilities-to-access-cervical-screening>

**PHE Screening and Immunisation Leads** to engage these leads in further consideration of actions to improve services and systems and to understand how these findings can feed into national work e.g. inequalities strategy

- Consultant in Public Health for Antenatal and Newborn Screening within NHS England (London) to **discuss with PHE Screening Quality Assurance colleagues and consider how presentation of this work could be incorporated into screening coordinator forums** to further disseminate findings, encourage discussions and initiate consideration of changes to services and systems

As mentioned above, an output of this evaluation will be a piece for the PHE screening blog and this will highlight systems issues, as well as feedback on the easy guides.

**Further blogs for the PHE screening blog could be authored by front line professionals** sharing their experience and best practice around ANNB screening and people with learning disabilities. As an output of this evaluation a **key contacts will be shared with PHE colleagues** who may be willing to author such blogs.

As a further output of this evaluation **approaches will be made to publish a summary of the findings in suitable midwifery and learning disability publications** to enable wider engagement with professionals.

## 10 Limitations

Limitations of this evaluation are acknowledged. The participants in the qualitative feedback and in the nationally disseminated online survey were self-selecting and therefore cannot necessarily be considered to be a representative sample across all professionals or people with learning disabilities. Findings from this small sample cannot automatically be generalised to all London units or nationally. The themes evident in this evaluation may not be not exhaustive and it is acknowledged there is variation in units, services, resources and views of people both across London and nationally. With these limitations in mind, however, the key themes from the London based in-depth work and national survey were consistent and recommendations stem from this consistent feedback.

## 11 Appendix

### 11.1 Appendix 1: Topic guide for semi-structured interviews with professionals, providers, voluntary sector, advocacy and support workers

1. How are women with learning disability picked up by maternity / ANNB services in order to receive appropriate support?

Probes:

- At what point are women who need extra support recognised/flagged?
- How does this process work - How timely is it? Are all women with learning disabilities captured?
- What pathways are in place for these women to support decision making around ANNB screening?. What 'reasonable adjustments' are made? Are other professionals/ support workers involved?
- What sort of numbers of women with learning disabilities in your in unit / service per month/ or year?. (Is data available or estimates?)

2. Are you aware of the PHE 'Screening tests for you and your baby' easy guide?

Probes:

- How did you find out about it? Any formal or informal awareness raising or guidance given locally when it was launched or since?
- If aware are they using it? Any formal or informal training or support given to use it?
- Who are professionals using the easy guides with? What do they perceive counts as eligibility to use easy guide with? Other groups than learning disability? How many per year from learning disability group and from other groups?
- Is the use of the easy guide documented in paper or electronic records and can this be audited?
- How are you using the easy guides e.g. printing off, sharing/looking at online, using in consultation as part of a discussion with women, giving them out to read at home
- Do they use all the sections of the guide – if not which ones, are some more useful than others?
- Are some points in the antenatal and postnatal pathway more useful to have an easy guide for or more amendable to using them?

- What do you think of the content:
  - Accessibility (is the content readable and understandable, and provided in the correct format?)
  - Authenticity (is the information considered reliable and honest?)
  - Balance (is the content seen as biased? Is the purpose of it clear?)
  - Impact (how does the content affect the reader's opinions or feelings, did the content of the easy read make it easier to explain for the professional and easier to understand for the user?)
  - Usability (does the content help the reader make a decision?)
- Suggestions for PHE for improvements / other supporting materials /resources - What other formats would be useful? DVDs, online films/animations etc?

3. What other materials / resources are you aware of to support women with learning disability and maternity/newborn care generally or ANNB screening more specifically.

Probes:

- Do they use these?
- If so in conjunction with PHE easy guide or instead of PHE easy guide?

4. Who attends appointments with women who have learning disability?

Probes:

- What is the involvement of these people in information provision during pregnancy and newborn period more generally and use of easy guide more specifically?

5. What training do you have in supporting women with learning disabilities?

Probes:

- How equipped do you feel to communicate ANNB screening information, options and support decision making?
- Any suggestions to build capacity in this area or good practice to highlight?

6. What gaps do you see in relation to information provision on ANNB screening to women who have with learning disabilities?

7. Do you have any best practice examples to share?

## 11.2 Appendix 2: Online survey

### **Evaluation of the provision of antenatal and newborn screening information for women with learning disabilities in London, including evaluation of PHE's [Screening tests for you and your baby: easy guides](#)**

Questions for embedded survey in PHE screening blog

#### Introduction and consent to proceed

NHS England (London Region) wants to better understand the provision of information on antenatal and newborn screening to women with learning disabilities in London. This includes an evaluation of PHE's [Screening tests for you and your baby: easy guides](#). We are working with PHE Screening on this. We plan to interview a number of professionals and others who support women to get their views.

To understand if the findings from our interviews are shared by a wider range of people across England we have created this online survey. We would like to gather the views of anyone who may support women with learning disabilities through maternity or newborn care generally or in accessing the antenatal and newborn screening programmes specifically.

The survey should take about 15 minutes to complete.

We will use the information in discussions aimed at improving the antenatal and newborn screening programme, easy guides and related products.

Any information you give will be kept anonymous.

I confirm I hold a role where I may potentially support a women with learning disabilities through maternity or newborn care or to access the antenatal and newborn screening programme. (Tick box)

#### Section 1: About you

What part of England are you based in (if unsure please consult this [map](#)):

- North East
- North West
- Yorkshire and the Humber
- East Midlands
- East of England
- West Midlands
- South East

- South West
- London

Which of the following best describes your role:

- Midwife, obstetrician or other maternity health professional (involved in clinical care of pregnant women)
- Antenatal and newborn screening professional (involved in commissioning or delivery of ANNB screening programme specifically)
- Learning disability nurse or other learning disability professional
- Other health professional
- Voluntary sector organisation
- Academic with interest in this area
- Advocate / supporter for women with learning disabilities or their families
- Other, please state

Have you got direct experience of providing women with learning disabilities with information on antenatal and newborn screening?

- Yes
- No
- Please give more details

Have you had any training in providing information to women with learning disabilities?

- Yes – general training on working with people with learning disabilities
- Yes – specific training in communicating in context of maternity/ antenatal and newborn screening
- No
- Comments

How equipped do you feel to communicate antenatal and newborn screening information, options and support decision making with women with learning disabilities?

- Not at all
- Somewhat
- Moderately
- Well
- Comments

Section 2: Awareness of Easy guide

Were you aware of the PHE 'Screening tests for you and your baby' easy guides before being asked to complete this survey?

- Yes
- No, go to section 4

If yes:

- How did you find out about it?
  - PHE screening blog
  - Local formal communication
  - Local informal communication/word of mouth
  - Google / other search while looking for materials
  - Other
- Has there been any formal or informal awareness raising or guidance given locally about using the easy guides?
  - Yes
  - No
  - Please give more details
- Has there been any formal or informal training or support given locally about using the easy guides?
  - Yes
  - No
  - Please give more details

### Section 3: Use of easy guides

Have you used screening tests for you and your baby' easy guides as part of your work?

- Yes
- No, if no go to section 4
- other

If yes/other:

- How many times have you used it
  - Once or twice
  - 2 – 10 times
  - More than 10 times
- Who have you used it with?
  - Women with learning disabilities themselves
  - Carers or supporters of women with learning disabilities

- Other people please state:
- How did you use the easy guides?
  - Printing off and using hard copy
  - Using online version on a device
  - Other, please state
- Did you go through the easy guides in the consultation?
  - Yes, all of any relevant section
  - Yes, parts of relevant sections
  - No, please tell us more
- Did you give a hard copy to take home?
  - Yes – to women herself
  - Yes – to carer or supporter
  - No
  - Comments
- Did you give the web link in hard copy to take home?
  - Yes – to women herself
  - Yes – to carer or supporter
  - No
  - Comments
- Have you used all the easy guide sections?
  - Yes
  - No
  - Which sections have you used most?
  - Are some sections more useful? If so, which?

#### Section 4: About the guide

In your opinion how well does the easy guide perform in the following areas?

- Accessibility (is the content readable and understandable and provided in the correct format?)
  - Poor
  - Fair
  - Good
  - Very good
  - Comments
- Authenticity (is the information reliable and honest?)
  - Poor
  - Fair



- Good
  - Very good
  - Comments
- Balance (is the content biased? Is the purpose of it clear?)
  - Poor
  - Fair
  - Good
  - Very good
  - Comments
- Impact (how does the content affect the reader's opinions or feelings, did the content of the easy read make it easier to explain for the professional and easier to understand for the user?)
  - Poor
  - Fair
  - Good
  - Very good
  - Comments
- Usability (does the content help the reader make a decision?)
  - Poor
  - Fair
  - Good
  - Very good
  - Comments

#### Section 5: Improvements and other materials

Do you have any suggestions to make improvements to this easy guide?

Do you have any suggestions to improve information provision to women with learning disabilities on antenatal and newborn screening in general?

Do you know of any other materials / resources to support providing information to women with learning disability about maternity/newborn care generally or antenatal and newborn screening more specifically?

- Yes
- Please give details
- No

If yes do you use these?

- In conjunction with PHE easy guide
- Instead of PHE easy guide?
- Aware of them but don't use them
- Other/comments

Thank you and invite to interview

Thank you for taking the time to answer these questions.

If your role is based in London and are happy to be contacted for a more in-depth interview on this topic please leave an email address here. This information will only be seen by the NHS England/PHE staff members analysing the survey results and will be kept confidential.

### **11.3 Appendix 3: We communities twitter chat supporting materials – questions tweeted and summary of chat (further details at <http://www.wecomunities.org/tweet-chats/chat-details/4201>)**

#### **Questions tweeted**

- Are you aware of the 'screening tests for you and your baby' easy guides ([goo.gl/ow1efJ](http://goo.gl/ow1efJ)) and have you or any of your service users used them?
- What are your views on the 'Screening tests for you and your baby' easy guides ([goo.gl/ow1efJ](http://goo.gl/ow1efJ)) ?
- Are there any improvements you'd suggest?
- Other than easy guides, what would help explain screening in pregnancy for women with learning disability?
- How do your local services meet the needs of women with learning disabilities for information on screening in pregnancy/ for their newborns?
- In your area are you aware of dedicated pathways or a lead for pregnancy in women with a learning disability?
- What would best practice be when it comes to providing information to a pregnant woman with a learning disability?
- What maternity services should be in place?
- Are you aware of services in your area for women with a learning disability who are pregnant? Please share examples.
- How can information and systems for women with learning disabilities in pregnancy be improved locally or nationally?
- How could health professionals better deliver information on pregnancy to women with learning disabilities?
- What experiences have you had surrounding pregnant women with a learning disability?
- Following this chat how will you use these easy guides in your practice?

#### **Summary of WeLDNs Maternity/Screening twitter chat that took place 3<sup>rd</sup> July 2018 at 8:30pm (Hosted by WeLDnurses using #WeLDNs)**

##### **Easy guides and awareness of this resource**

The 'screening tests for you and your baby' easy guides hadn't been seen by all on the chat, although there were some encouraging examples of wider awareness and use; such as a student midwife bringing them to a baby group. There was a general feeling these materials should be standard in all maternity services and many people on the chat committed to share these materials with colleagues and increase awareness. There were suggestions around engaging student's nurses / midwives, sharing resources and making them more aware early in training and suggestions of

using local intranet systems such as 'question of the week' auto loading on trust on PCs to share information and resources links.

### **Developing video resources around screening /maternity**

The development of videos resources around screening and maternity appeared to be positively supported. There were lots of tangible suggestions for consideration in developing these including:

- Co-production - engaging people with learning disability and advocacy groups in developing and making the resource (with people with learning disability appearing in the video)
- Breaking down content into small sections and using terminology / visuals to get the message across
- Utilising short video formats that can be re watched as needed
- YouTube as a platform can be downloaded on to handheld devices

### **Other supporting materials**

Suggestions were received of other ways information on screening in pregnancy could be shared including interactive apps, visual maps, and sequence strips.

### **Top tips for supporting women with learning disability**

A variety of suggestions were made that professionals could use to guide them in supporting women with learning disability in pregnancy (and potentially could be included in a 'top tips' type document PHE screening is looking to create). These included:

- Tailoring approach - using a variety of communication tools to ensure it meets individual's needs. Finding out how they need the information to be presented and then provide that e.g. symbols, signing, film
- Being aware of the terminology used - positive and professional
- Ensure enough appointments to re-visit information and check understanding
- Services can differ and understanding how to navigate the local offer would also be beneficial. Tailoring information to the persons individual experience is good – suggestions include using polaroid / phone camera pictures to create and share bespoke information for the local context
- Format of a 'Top tips' document - one page, designed as posters for offices or clinic rooms, and as a screen saver on trust computers.

### **Wider systems issues**

Variation was evident in the configuration of services and whether there were leads /point people / specialist midwives for learning disability. The feeling seemed to be there should be some kind of link midwife specifically for women who have a learning

disability and more multidisciplinary team working between midwives/ screening professionals and learning disability community nurses/ liaison teams.

There was acknowledgement that, as with everyone, women with learning disability should get the services they need and “reasonable adjustments” made but making these adjustments was felt by some to be an area with uncertainty around it and staff need support to do this.

Embedding in midwifery training a module on identifying, communicating with and supporting women with learning disabilities and improving links with social services and other care providers was also raised.

### **Moving forward in an collaborative way**

There seem to be a genuine enthusiasm in this chat to engage further to improve materials for ANNB screening, but questions about best way to do this. This will be discussed further with the PHE screening team, who are keen to have support and key contacts they can call on. This was coupled with a sense that people would like to see more networks of different professionals coming together to share skills and best practice rather than just when a need arises, so much we can learn from one another.

## 11.4 Appendix 4: Readability of easy guide by US School grade and corresponding age approximations

Easy guide	SMOG US grade on online-utility <sup>16</sup>	SMOG US grade on readable.io <sup>17</sup>	Approx. age equivalent of US grade SMOG scores	Average US Grade score on readable.io	Approx. age equivalent of average US grade score <sup>18</sup>
Screening for hepatitis B, HIV and syphilis	U.S. grade level 8.93	U.S. grade level 9.2	13 – 15 years	U.S. grade level 6.7	11 to 12 years
Screening for sickle cell disease and thalassaemia	U.S. grade level 9.13	U.S. grade level 10.7	14 – 16 years	U.S. grade level 8.8	13 to 14 years
Screening for Down’s syndrome, Edwards’ syndrome and Patau’s syndrome	U.S. grade level 8.53	U.S. grade level 7.4	12 – 14 years	U.S. grade level 6.2	11 to 12 years
Screening for problems with the baby’s body	U.S. grade level 6.67	U.S. grade level 6.5	11 – 12 years	U.S. grade level 4.4	9 to 10 years
Screening for eye problems for pregnant women with diabetes	U.S. grade level 6.87	U.S. grade level 6.9	11 – 12 years	U.S. grade level 5	10 to 11 years
Looking at your baby’s heart, eyes, hips and balls (testes)	U.S. grade level 6.57	U.S. grade level 6.7	11 – 12 years	U.S. grade level 5.1	10 to 11 years
Looking at your baby’s hearing	U.S. grade level 6.73	U.S. grade level 6.5	11 – 12 years	U.S. grade level 4.6	9 to 10 years
Blood spot tests	U.S. grade level 7.94	U.S. grade level 8	12 – 14 years	U.S. grade level 6.2	11 to 12 years

<sup>16</sup> [https://www.online-utility.org/english/readability\\_test\\_and\\_improve.jsp](https://www.online-utility.org/english/readability_test_and_improve.jsp)

<sup>17</sup> <https://readable.io/text/>

<sup>18</sup> Approximate age taken from <http://www.free-for-kids.com/uk-us-education-systems.shtml>